Washington State Cancer Registry
Technical Notes and Data Sources

Background

In 1990, RCW 70.54.230 made cancer a reportable condition in Washington and mandated the Department of Health to establish a statewide cancer registry program. Under this mandate, the Department established the Washington State Cancer Registry (WSCR) in 1991. The registry is dedicated to fulfillment of the legislative intent "...to establish a system to accurately monitor the incidence of cancer in the state of Washington for the purposes of understanding, controlling, and reducing the occurrence of cancer in this state." Since 1994, funding for WSCR has been provided, in part, through the Centers for Disease Control and Prevention's National Program of Cancer Registries. This program is designed to standardize data collection and provide information for cancer prevention and control programs at the local, state, and national levels.

Data Collection

Cancer cases are collected through a combination of contracts with two regional cancer registries and cases from independent reporting facilities (such as hospitals and clinics) with in-house cancer registry programs. The contractors and reporting facilities are responsible for case-finding, abstracting information on cancer from medical sources, and reporting cases to the statewide registry. The Cancer Surveillance System (CSS) of the Fred Hutchinson Cancer Research Center provides data on cancer cases from 13 counties in Western Washington, covering the majority of the state's population including the largest urban center of Seattle. CSS has been in operation since 1974 as a participant in the Surveillance Epidemiology and End-Results (SEER) Program of the National Cancer Institute.

The remainder of the state is covered by reporting facilities with in-house cancer registry programs and the Walla Walla-based Blue Mountain Oncology Program (BMOP). BMOP is a consortium of cancer registries from 14 health care facilities in the Walla Walla, Tri-Cities, Sunnyside and Spokane areas. BMOP provides data from these facilities to WSCR. In addition, under contract to the Department of Health, BMOP provides staff to collect cases at facilities that do not have in-house cancer registries. WSCR also conducts regular data exchanges with cancer registries in 30 states. Most of Washington's out-of-state cases are reported by Oregon and Idaho, followed by Texas and Arizona.

Cancer cases are identified through reports from hospitals, pathology laboratories, radiation oncology centers, ambulatory surgical centers, cancer treatment centers, and physicians. Once the case is identified, an abstract of cancer information is completed within six months and quality assurance activities are carried out by the contractors and reporting facilities. Data files are transmitted from the contractors and reporting facilities to the state on a regular basis. WSCR is responsible for merging the data and finalizing the statewide data set, overall data quality assurance in accordance with national standards, and dissemination of cancer information to assist with cancer prevention and control efforts statewide.

The cancer reporting rules (246-102 WAC) currently define reportable cancers as "any malignant neoplasm, with the exception of basal and squamous cell carcinoma of the skin." Also specifically included are: 1) basal and squamous cell carcinoma of the external genital organs (vulva, labia, clitoris, prepuce, penis, anus, scrotum); 2) all brain tumors; and 3) cancer in situ, except cancer in situ of the uterine cervix. The legally required data for cancer reporting include patient demographics (such as age and sex) and medical information (such as type of cancer and date and stage at diagnosis) for all newly diagnosed cancers. Copies of Washington's cancer reporting legislation and regulations are available on request.

Report Contents

This report includes a summary of incidence and mortality for all cancers combined and for the 24 cancer sites most frequently diagnosed in Washington residents. Incidence data include cases newly diagnosed between January 1, 2000 and December 31, 2000, and reported to WSCR as of September 2002. This information covers the entire state and also includes new cases of cancer among Washington residents diagnosed in other states, such as Oregon and Idaho. Mortality statistics include deaths among Washington residents that occurred in 2000 where the underlying cause of death was cancer. The cancer may have been diagnosed before 2000. As with incidence, mortality data include Washington residents who die out-of-state.

The following material briefly describes the tables, graphs and charts in this report; the statistical methods used to produce each table, graph or chart; and special considerations for interpreting the data.

Tables, Charts and Graphs

Data Definitions and Sources

The Washington State Cancer Registry provides the number of new cases (incidence) of cancer as described above. Based on estimates of the expected number of cancer cases, the registry includes more than 95% of cases. Each cancer is coded to an International Classification of Diseases Oncology (ICD-O) code. The data definition provides the ICD-O codes used in each section. We have used definitions that are consistent with those used by the National Cancer Institute's SEER program.

The Washington State Department of Health, Center for Health Statistics provides information from death certificates on the number and causes of death. According to the National Center for Health Statistics, more than 99% of all deaths occurring in the United States are registered in the death certificate system. Accuracy of reporting specific causes of death varies since classification of disease conditions is a medical-legal opinion subject to the best information available to the physician, medical examiner, or coroner certifying the cause of death. We obtained the number of cancer deaths from the Vital Registration System Annual Statistical Files, Washington State Deaths 1980-2000 CD-ROM issued October 2001.

From 1980 –1998, the underlying cause of death was coded using the International Classification of Diseases, 9th Revision (ICD-9) coding system. Consistent with national requirements, beginning with deaths occurring in 1999, the Department of Health began using the International Classification of Diseases, 10th Revision (ICD-10). While the change from the ICD-9 to the ICD-10 resulted in substantive changes in rates for some causes of death, the effect of the coding change is minimal for cancer. For more information on the change from ICD-9 to ICD-10, see Comparability of Cause of Death Between ICD-9 and ICD-10: Preliminary Estimates.

The data definition provides the ICD-10 codes used in each section. We have used definitions that are consistent with those used by the SEER program. For some cancer sites, including colorectal, liver, and leukemia and multiple myeloma, the SEER coding differs from the National Center for Health Statistics coding which may be used in other reports. Therefore, before comparing information from different reports, one must be sure that the definitions are consistent.

Population data, necessary for the calculation of rates, for 1992 – 1999 are intercensal interpolations developed by the Washington State Office of Financial Management, based on 1990 and 2000 census data, Washington State births and deaths, and estimates of in and out migration. Population data for 2000 are from the 2000 US Census. All population data were obtained from Office of Financial Management, September 2001 release.

Incidence and Mortality Summary

These tables provide the number of new cases of cancer and the number of cancer deaths for Washington State residents in 2000. Since the numbers of new cases and deaths depend, in part, on the size of the population, we converted numbers to rates (e.g., the number of cases per 100,000 people) so that they may be compared among different regions or populations. For diseases, such as cancer, where incidence varies with age, the rates are age-adjusted to minimize the effect of different age distributions when comparing two geographic regions or populations.

Following national standards, we have age-adjusted rates to the 2000 US standard population. **When making comparisons, one must be careful to compare age-adjusted rates that are adjusted to the same standard population.** Age-adjusted rates should not be compared to rates that are not age-adjusted (i.e., crude rates). Detail on our age-adjustment method is provided in Appendix A.

The final row of the incidence tables provides age-adjusted incidence rates from the eleven National Cancer Institute's SEER regions. These rates are from SEER*Stat version 4.2 CD-ROM public-use file containing data from 1973 – 1999, issued April 2002. The final row of the mortality tables provides age-adjusted mortality rates for the United States. The US mortality data were obtained from the SEER CanQues program (http://seer.cancer.gov/ScientificSystems/CanQues/). The SEER programs do not include data for 2000. Since cancer incidence and mortality rates do not change rapidly, we have provided 1999 national data for comparison.

Stage at Diagnosis

Stage at diagnosis refers to how far a cancer has spread from its site of origin when it is diagnosed. The stages, in order of increasing spread, are in situ, local, regional and distant. Cancers staged as local, regional, or distant are referred to as invasive. The reader should note that many publications of the National Cancer Institute and the Centers for Disease Control and Prevention report rates of invasive cancer only. Thus, caution must be exercised when comparing incidence rates contained in different reports.

The WSCR data contain the stage of disease at diagnosis coded according to the SEER guidelines.

In Situ	A tumor that fulfills all microscopic criteria for malignancy, but does not invade or penetrate surrounding tissue.
Localized	A tumor that is invasive but remains restricted to the organ of origin.
Regional	A tumor that has spread by direct extension to immediately adjacent organs or tissues and/or metastasized (spread through the blood stream) to regional lymph nodes, but appears to have spread no further.
Distant	A tumor that has spread by direct extension beyond the immediately adjacent organs or tissues, and/or metastasized to distant lymph nodes or other distant tissues.
Unstaged	Insufficient information available to determine the stage of disease at diagnosis.

We have provided the frequency distribution of cases according to their stage at diagnosis.

For most cancers, diagnosis at an early stage (in situ or local) results in improved survival. One standard measure of survival is the five-year survival rate that estimates the proportion of individuals with a given cancer who are living five years after diagnosis. We have not developed five-year survival rates for Washington state residents. However, we have provided the SEER five-year survival rate for each cancer. These statistics were obtained from SEER*Stat version 4.2 CD-

ROM public-use file containing data from 1973-1999, issued in April 2002. This data file provides survival rates by stage of disease at diagnosis. The national five-year relative survival rates are calculated for cancer cases diagnosed between 1992 and 1998, based on follow-up of patients through 1998. The National Cancer Institute defines the relative five-year survival rate as the likelihood that a patient will not die from causes associated with their cancer within five years. The SEER*Stat program calculates this rate using a procedure described by Ederer, Axtell, and Cutler (1961) whereby the observed survival rate is adjusted for expected mortality. It is always larger than the observed survival rate. (Ries et al., 1999)

Age-Specific Incidence Rates

Age-specific rates show the variation in cancer incidence by age group for males, females, and the total population. The age-specific rates are the average rates for 1998 – 2000. Combining three years of data reduces the potential that annual changes in small numbers for some age and sex groups will result in fluctuations that are difficult to interpret.

Incidence and Mortality Rate Trends

These charts provide incidence and mortality rates for several years for Washington residents per 100,000 population, age-adjusted to the US 2000 standard population. (See “Incidence and Mortality Summary” for a discussion of age-adjusted rates.) These tables show both changes in rates over time and the relationship between cancer incidence and mortality. As described in “Data Definitions and Sources” above, the Department of Health began using the ICD-10 coding system for causes of death occurring in 1999. For most types of cancer, the effect of this change is minimal. Nonetheless, caution must be exercised in interpreting apparent trends in cancer mortality across the years of the coding change. For this reason, the trend chart shows a break between the mortality rates for 1991 – 1998 and the 1999 mortality rate.

Incidence and Mortality Rates by County

We have presented the average annual age-adjusted cancer incidence and mortality rates for Washington residents per 100,000 population by county. (See “Incidence and Mortality Summary” for a discussion of age-adjusted rates.) Because of the small size of many counties and the relative rarity of some types of cancer, the incidence and mortality rates based on one year of data are not stable (i.e., there is some random fluctuation in rates from year to year). Therefore, for county rates, we have combined three years of data (1998 – 2000) to compute average annual age-adjusted rates for the three-year period.

The state rates and 95% confidence intervals are included for comparison purposes. While the incidence and death statistics in this report are not subject to sampling error, they may be affected by random variation. The confidence interval is used to describe the range of that variation.

Generally, when the confidence interval for the area of interest does not overlap with the confidence interval for the comparison area, we say that the two areas are statistically significantly different, i.e., the difference between the two rates is more than that expected by random variation or chance. However, if we are making many comparisons, we may still find statistically significant differences just by chance. In fact, with a 95% confidence interval, we expect that 5% of the comparisons will be statistically significant by chance. Thus, with 39 counties and 24 cancer sites, we might see as many as 45 instances where the rate for a county is statistically significantly different from the state rate just by chance.

Even with a three-year average, rates may fluctuate widely when there are a small number of cases. Therefore, we omit the rate and confidence intervals when there are fewer than five cases for the three-year period. Details of our methods for calculating confidence intervals are in Appendix A.

What's Missing

Information on Cancer by Race

Following current guidelines from the federal Office of Management and Budget, the 2000 US census allowed people to select more than one race; however WSCR currently reports only one race for each person. Thus, for race the population data (or denominators) for calculating rates do not correspond to the cancer cases (or numerators). The Washington State Department of Health is working with other state and national organizations to resolve this issue. We anticipate that the WSCR report for 2001 cancer data will again include cancer rates by race.

Prevention, Early Detection, and Treatment

Illness and death due to cancer are increasingly preventable through the application of growing knowledge about the causes of cancer, improved screening and early diagnosis techniques, and more effective treatment. Extensive information on prevention through changing modifiable risk factors, early detection through routine screening, and preferred treatment modalities is available. We have not attempted to reproduce this information in detail. We have provided a resource list in Appendix B for those interested in more detail.